Reflections on Cohort studies, life course and research into ageing

Carol Brayne

Cambridge Institute of Public Health
University of Cambridge

Humans are the product of the Big Bang, the solar system and evolution. This may sound trite, but it is also our understanding of each person's existence on this planet. It reminds us that everything about us, including our intellect, is the product, and needs to be framed in an understanding, of our origins and our context. The history of human striving to understand ourselves, other living things, physiology and pathophysiology has been shaped by our constantly changing social and cultural context and history. Each successive generation will have some similarities and some differences from the earlier ones. Research to understand how our health is maintained or declines across the life course is part of this striving for understanding. We seek evidence for translation beyond anecdotal observation in order to be able to control, to varying extents, our destiny. This could be seen as one of the contemporary existential quests, but one based in enlightenment and empiricism.

Much of our current understandings, paradigms, methods and interpretations are products of the enlightenment and its impact on global society through the industrial revolution. Epidemiology is part of this too. Within the overarching discipline of Public Health, epidemiological methods have been developed and continue to be shaped by the opportunities emerging from biomedical science. But human experience and the quality of our existence within these contexts is influenced by far more than the outputs of reductionist approaches – or is it? The most enthusiastic empiricists believe that with Big Data and ever greater extensions of our methods we will be able to achieve some sort of unity between the 'quantified' self and the experienced self. Others might argue that this is fanciful, over weaning and that increasing movement towards this will bring us closer to the brain as machine, and then on to the machine being merged with the human and a possibly a future where humans are subservient to 'the machine' as described so presciently by E.M. Forster in his short story 'The Machine Stops'. What does this have to do with life course epidemiology and is this just amateur musing?

Others argue that humans have accrued knowledge through observation, experimentation and experience across societies and generations. These outputs are ancient wisdoms garnered across human history, passed down and changed through experience across generations of humans within and across different global settings. These are captured in legends, poetry, literature, religious texts and history. These tell us that society is important, early life, our environment and the way we live our lives all influence whether and how we age. Life course epidemiology and public health approaches allow researchers to work in an interdisciplinary manner to bring the most extraordinary modern scientific approaches alongside understanding of culture and society and often bring us

back to these ancient lores but with empirical (and therefore more acceptable to post enlightment society) evidence. To some extent during the last century, with the 'white heat' of science, earlier knowledge was set aside and man as machine replaced it. This has included epidemiological approaches where, within the pure research fields, a narrow research agenda has been pursued, with single exposure, single outcome reifying the single disease thinking.

Cohort studies (fixed) which set a population at outset and then follow this group over time have provided empirical evidence to support much ancient lore, as well as identifying specific protective and noxious elements across life that might be influenced by societal and individual approaches to future health. They have provided rich opportunities for the testing of specific hypotheses and also broader testing of hypotheses not originally part of their justification. This has led to some extraordinary successes, such as in understanding the risks associated with smoking, and single risk factors for heart disease. But with an ageing globe, it has become increasingly clear that that this is not sufficient for societies in which wellbeing and an optimal life course with a good death is highly valued. Add to this the threats we see to human sustainability and earlier narrow epidemiological approaches, whilst having their place, need to be replaced by new ways of looking at societies across time and across varying life courses using a range of disciplines that can bring meaning to reductionist approaches. As highlighted in this special edition cohort research greatly enriches our understanding of particular life stages and particular outcomes.

However, we also need to understand how these studies themselves are subject to fashion, and make assumptions about the nature of exposure and the evolution of disease across time. Largely cohort studies have tended to accept their contemporary diagnostic paradigms, applying them to populations and becoming ever more biomedical. Few studies have used the biomedical measurements to test whether the nature of disease, intermediate states and and disorders are changing and whether their implications for lived life are changing. Because it is so difficult to establish funding for cohort studies and they have to compete with very different types of studies within the currently accepted paradigm of a given disorder, cohort studies have not addressed such basic questions (seen by granting Boards as boring) instead orientating themselves to attach to the coat tails of the latest cutting edge cellular, molecular and imaging technologies. This has been successful in capturing large amounts of money for cohort survival and for laying down large volumes of data in archives (e.g. moving from genetics to genomics to –omics and mass imaging in particular), but it could be argued that this has not led to major insights which benefit populations in the short or medium term. This lack of obvious benefit could, to some extent, be seen to be driving the push for merging datasets into Big Data in the belief that this will provide the promised insights that had not otherwise be apparent. This moves us a long way from lived life for individuals within communities.

Cohort studies and particularly those that are long running can look in different directions and have the ability to study many things. The longer they run the

more angles can be examined and some are only appreciated after decades with several of these illustrated here. Often the findings are not there by original intent – they are the serendipity and creativity of the researchers who have to keep them going in a harsh environment.

Thus we have a richness of findings, not by strategic design, but rather influenced by history, political and social fashions for funding (does it win you votes and will it look good in the media?). It could be argued this is topsy-turvy and that we should have a more strategic approach to such work. Some might counter-argue that there is indeed a strategic view as evidenced by various reports on the value and existence of cohorts such as that conducted by the UK's medical research council recently. But strategic views do not take the major challenges of human society into account, inequity, mass migration, unrest, whether lack of representation of the population in studies matters, and the whole community rather than a focus on the individual into consideration. A wider perspective seems necessary at this moment in history, in which classical epidemiology and cohorts take their place but with attention to the wider challenges to society and major forward thinking about investment that seeks not to address short term questions but longer term ones which go well beyond mining cohorts for drug discovery and opportunities to expand the market (and thereby UK plc). This should include an assessment of the gaps in representation of contemporary society that exist, as well as the opportunities for new thinking to ensure the value to society in the short, medium and long term from the existing cohorts.